

At the crossroads: Personal and professional perspectives on long-term care pathways for older women living with dementia

What you need to know:

The researchers examined administrative data and compared it with personal stories and narratives to analyze the experiences of older women with dementia in long-term care (LTC). A life-course perspective (LCP) supports this research because it recognizes the diverse life experiences of individuals and assists with our understanding of the care journeys of older women living with dementia.

What is this research about?

The long-term care (LTC) sector includes publicly and privately funded services ranging from home care (HC) which is care in the person's home, and facility-based residential care (RC), which is often known as a nursing home. These services occupy important places in the health care continuum, but are often criticized as being fragmented and poorly integrated, as they are often delivered in silos, and no one sector is responsible for continuity across the system.

The researchers use the metaphor of Janus, the two-faced, Roman god of beginnings and transitions, to explore how their personal and

professional worlds are interwoven, as family members and researchers.

What did the researchers do?

The researchers examined administrative data on 3,717 older women with dementia receiving LTC in British Columbia (BC), Canada from 2008 to 2012, and then compared it with personal narratives—the stories of their mothers who made the transition from HC into RC.

The researchers focused on two questions:

1. How do our quantitative data map onto our mothers' experiences?
2. What lessons do our mothers' experiences offer for the care of older women with dementia?

To answer the questions and understand the health and service pathways of older women with dementia, they used the LCP which is influenced by demographics (age, gender, marital, etc.); health status; care contexts; linked lives (role of family); and personal choices and control.



UVic study explores personal stories along with administrative data on the experiences of older women with dementia in the long term care system (Photo: sarcifilippo from Pixabay).



What did the researchers find?

The quantitative data revealed that the HC to RC transition is the most common LTC pathway for women with dementia, who are most likely to be widowed and living alone in suburban areas. On entry into RC, they have greater frailty in terms of activities of daily living, cognition, aggression, and incontinence.

The researchers' personal narratives of their mother's experiences suggest that transitioning through LTC for women with dementia, is often much more complex in real-life. Attention is drawn to public and private services, hospitalization patterns, and substantial communication gaps in the care experienced by their mothers and families.

The quantitative data for the study was based on the number of women who had a complete and valid Resident Assessment Instrument (RAI) assessment (clinical and functional assessments) upon entry into LTC, whether HC or RC, between 2008-2012.

How can you use this research?

This research is relevant for health care planners, decision makers and policy makers of the LTC system as it improves our understanding of the pathways, predictors, and experiences of older persons with dementia and their families. This research is also meaningful for resource allocation decisions; local, national, and international comparisons; and in promoting the care of frail individuals under a philosophy of "continuous care" rather than discharge management.

Future research should continue to use longitudinal quantitative and qualitative studies and the LCP framework to understand individual experiences of LTC through lenses of diversity, linked lives and family dynamics, alongside shifting social, historical, and organizational contexts.

About the researchers

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Keywords

Dementia; long-term care; transitions; trajectories; personal narratives; nursing homes; transitional care; residential care; home care; and aging.

Citation

Cloutier, D. & Penning, M. (2017). Janus at the Crossroads: Perspectives on Long-term Care Trajectories for Older Women with Dementia in a Canadian Context. *The Gerontologist, Special Issue: Aging-It's Personal*. 57 (1), 68-81.
<http://gerontologist.oxfordjournals.org/content/early/2016/11/15/geront.gnw158.full.pdf+html>.

Content for this Research Snapshot was co-created by [UVic's Research Partnerships and Knowledge Mobilization unit](#) and Dr. Denise Cloutier.